ALERT

THE UNIVERSAL FELLOWSHIP OF METROPOLITAN COMMUNITY CHURCHES

News from the UFMCC on AIDS Legislation, Education, Research and Treatment.

February 1993

Waco, Texas: A Small MCC's AIDS Ministry Program

How does a small MCC in a conservative, small city create an effective AIDS Ministry? MCC of Waco, Texas, with only 45 members, has worked closely with local HIV/AIDS service providers, and together they have opened a Daily Activities Center and a Food Bank for persons with HIV/AIDS, both housed at MCC Waco.

Alan Jones, a nursing student and the Lay Delegate from MCC of Waco, coordinates the Activities Center and the Food Bank at MCC Waco, through a contract with the McLennan County AIDS Resource and Educational Services (MCARES). In an interview with ALERT, Mr. Jones gives a lot of credit to the former pastor, Rev. Janice Skaggs, who recently moved to New Heart MCC in Tacoma, WA. "She was very instrumental in opening closed doors."

Cindy Dunlap, the manager of HIV/AIDS Services for the Public Health Service Department, elaborates, "The pastors of the church over the last five years [Rev. Roy Lenington and Rev. Jan Skaggs] have, in their own way, made an impact among their membership, but also in reaching other church ministers, and other open-minded individuals in the community. They have attempted to bridge the fear." Ms. Dunlap originally came to MCC Waco for help in reaching the gay community.

"That church, however small, has made a huge difference and impact on HIV services,..."

Cindy Dunlap, Manager of HIV/AIDS Services

"Rev. Lenington was a huge help to me at the start of the program five years ago. Rev. Skaggs took the church from there and built upon the foundations that were laid. Now MCC has a three-story building, while they were once in a store- front. The middle floor is the sanctuary, the top floor is for Sunday School classes, and the bottom floor is the Fellowship Hall, and houses the Activities Center and the Food Bank."

The Activities Center and the Food Bank are open Monday through Friday, from 10 a.m. to 2 p.m. The Activities Center has a TV and VCR, board games, arts and crafts, and once a month, an educational seminar is held. Alan is there every day, providing a dynamic presence, "full of energy, life, and pep!" according to Ms. Dunlap. The Center has become very important to clients who are homebound, but need to get out for awhile. Meals on Wheels pro-

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US AIDS Action Council Sets Four Point 1993 Agenda

With the hope that the new year may bring a significant turnaround in the fortunes of the AIDS community, the U.S. AIDS Action Council will focus in 1993 on increasing federal funding for AIDS-related programs, realizing health care reform, pushing for programs which can help prevent the transmission of HIV, and pressing for improved drug treatments.

"In other years, we have set our goals with an attitude of grim determination," notes AIDS Action Council Executive Director Daniel T. Bross. "This year, we have done so with a degree of hope. The national playing field has been leveled by the election of Bill Clinton to the Presidency, giving AIDS Action relatively better odds of accomplishing our agenda."

Among key issues the newly expanded organization will tackle are:

Prevention: AIDS Action Council will seek legislation promoting expanded and entirely restructured HIV prevention services and research programs. The council is now soliciting community input and evaluation of the current effort and hopes to shape and pass major legislation on this issue by year's end.

Health Care Reform: One of President Clinton's and AIDS Action Council's top priorities, the council participates in several coalitions seeking health care reform to promote the interests of people with HIV, such as expanded access to care, and coverage of long-term care, prescription drugs, and diagnostics.

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Paris, France: Urgent Need For AIDS Ministry Personnel

By Rev. Steve Pieters

During my visit to the new MCC Paris in November, 1992, I continually heard how terrible the situation is for persons living with HIV/AIDS in France. I pledged to the pastor, Caroline Blanco, and the members of MCC Paris that I would write about the situation for ALERT, and publish here in ALERT the need for a man to come to Paris to do AIDS Ministry.

I was genuinely surprised to find out how terrible the situation is in France. I had the image of Paris particularly as being very sophisticated sexually, and marvelously advanced in terms of AIDS education, prevention, and treatment. I could not have been more mistaken.

The first night I was in Paris, I stayed with a friend of the pastor's, who works as a nurse in one of the larger hospitals in Paris. She told me that all the hospitals are jammed with people dying from the complications of AIDS. She described how people do not get tested in France, because there is so much denial. The medications which help prolong life in people who are HIV-positive have no chance to be effective because people do not know they are carrying the virus until they have already been diagnosed with a major opportunistic infection. The denial continues because nobody wants to be known as dying from the complications of AIDS. Routinely, people are said to have died from the cardiac complications of a virus (as Rudolf Nureyev's death was recently reported). So the general population continues to live in denial, because they don't know that anyone is dying from AIDS.

The second night I was in Paris, I met with seven members of MCC, who further described the horrible situation they face. They told me that the French government essentially shut down all AIDS education efforts in 1985, following the much-publicized visit of Rock Hudson to Paris for treatment. The government reportedly did not want France to become a "haven" for people with AIDS. Although I did see some educational materials in French, I was told these were all published privately within the gay community, and there were no similar education efforts being made to the population at large.

AIDS action groups and social service agencies come and go quickly in France, since they are not supported by any public funds, just as lesbian and gay organizations have a history in Paris of closing as rapidly as they open. As a result, there is no place where people can go to get clear information on the transmission of HIV, nor is there anywhere for HIV-positive people to go for help and education about living with the virus.

When I asked how MCC Paris could step in to fill this void, Caroline Blanco and other members of MCC told me of efforts to gain access to hospital wards to minister to persons with AIDS, but hospitals will not release the information about which patients have AIDS, and her credibility as a pastor is questioned since she is not a Roman Catholic priest (i.e., male).

Similarly, the pastor has tried to reach gay men with AIDS in the gay bars of Paris, but it is extremely difficult for her, because in this heavily Roman Catholic country, many men are not ready to open themselves up to her ministry.

Caroline and the other members are hoping that they will be able to find a strong male minister who will be able to gain access where they haven't been able to. This man needs to have a working knowledge of French, he needs to be able to support himself, and he needs to have a strong sense of himself and his mission. They are praying in Paris that someone who fills this bill will feel called to join them. They are aware that some in the Fellowship may see this as sexist, because they need a man to open their AIDS ministry; but they ask that others try to understand that their culture is significantly different, and they cannot fight all the battles at once. Right now, they need strong male leadership to effectively minister in the AIDS crisis.

Caroline Blanco second from left, pictured with her lover Katherine, far left and with Rev. Elder Troy Perry and Rev. Elder Jean White.

There is also a great need for HIV/AIDS literature in French. Ms. Laurence Vergez, of Markens Liljer MCC in Copenhagen, Denmark, has agreed to translate the UFMCC pamphlets, "AIDS: Is It God's Judgement?" and "Spiritual Strength For Survival" into French. Any other materials in French which might be of help to MCC Paris' efforts should be directed to Caroline Blanco in care of MCC Paris.

Any man who feels qualified and called to AIDS ministry in Paris should contact Caroline Blanco at Centre de L'Esprit Liberateur MCC, 32 Rue Berzelius, 75017, Paris, France. ▼

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ALERT is a monthly newsletter containing information on AIDS Legislation, Education, Research and Treatment. The Editor is Rev. Dr. A. Stephen Pieters. For more information, or to send a donation, please write or call: ALERT, c/o UFMCC, 5300 Santa Monica Blvd., Suite 304, Los Angeles, CA 90029; (213) 464-5100.

VOICES THAT CARE

Compiled by Neal Hitchens

(Los Angeles: Lowell House, 1992)

Voices That Care: Stories and Encouragements for People With AIDS/HIV and Those Who Love Them begins with a portfolio of celebrities speaking to persons with HIV/AIDS. Elizabeth Taylor, Liza Minnelli, Cher, Phil Donahue, Arsenio Hall, Joan Rivers, Bea Arthur, and a number of other relate touching stories, or offer the simple wisdom of compassion. In his introduction, Neal Hitchens briefly tells the story of his own baptism into the world of HIV/AIDS, through his lover's illness and his own subsequent testing. Then he presents nearly 100 people affected by HIV/AIDS telling their own stories, in their own words.

A great diversity of people, primarily from the United States, relate their pain, their struggle, their joy, and their love for life as they live with HIV/AIDS. This book includes the voices of Susan Bluestein, widow of the actor Brad Davis; Alan Menken, telling the story of his Oscar-winning partner, Howard Ashman; Senator Tom Harkin, writing about Belinda Mason; Alison Arngrim, Dack Rambo, Michael Callen, and the Rev. Steve Pieters. But there are dozens of other, lesser known voices in this book, making a literary quilt which has as much power to move and inspire as the Names Project quilt.

This is a good book to give to persons who are newly diagnosed or are facing diagnosis of a loved one, because it gives encouragement and inspiration, while remaining firmly grounded in the reality of the experience of HIV/AIDS. ▼

WISE BEFORE THEIR TIME

International Stories from Persons with HIV

(Edited by Ann Richardson & Dietmar Bolle. London: Fount, An Imprint of Harper Collins Publishers, 1992)

In *Wise Before Their Time*, Ann Richardson and Dietmar Bolle present the personal stories of men, women and children living with AIDS/HIV. The candid reflections address the trauma of testing HIV-positive, learning to stay healthy, dealing with isolation or rejection, the changing nature of relationships, the role of spirituality, facing mortality, looking to the future, and more.

Emphasizing self-worth, self-help, and self-determination, these personal stories inspire, educate and comfort. "People with HIV/AIDS are often young men and women, who could feel highly vulnerable," says Ann Richardson in the preface. "Yet the central message of this book is the dignity with which they can face their situation. The individuals in these pages do not present themselves as 'AIDS victims' but talk instead of the joys of life and the fundamental values to which they have been drawn. It is this transcendence over their disease, not their vulnerability, which gives their voices real power. They have looked their own mortality in the eye and are wise before their time."

The people who tell their stories in this book are from around the world, with only two people from the U.S. The bulk of the people interviewed are from Europe, with a number from Africa, several from Asia, Australia, and Latin America. Anyone interested in gaining a more global perspective on what it's like to live with HIV/AIDS will find this book fascinating reading. ▼

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vides lunches for the clients every day. Alan Jones reports that on an average day, three to five people will take advantage of the Center.

The Food Bank provides the necessities of life to clients of MCARES, generally on a once-a-month basis. Mr. Jones states, "There are no limits, and no guidelines. It's up to me, but generally our clients each get four to five bags of non-perishable food, toiletries, and clothes." They have just obtained a freezer, and so they can now stock frozen dinners to distribute as well. Up until a couple of months ago, all the food was donated by church members and other interested members of the community. But recently, grants have been made available to MCARES, which is the primary contractor for state and federal funds for HIV/AIDS services. Now, Alan Jones buys the food for the pantry, and MCARES reimburses MCC for the cost.

In addition to these two major activities, the County also uses MCC as an anonymous testing site at least twice a month. The church does a weekly AIDS Prayer in their regular worship service. And church members have the opportunity to offer their pocket change each week, all of which goes to pay for emergency medications for persons living with HIVAIDS. Over the past two years, the church has raised over $2500 for this purpose, simply through these pocket donations.

Mr. Jones emphasizes that none of the church budget goes to AIDS Ministry. All of this activity is supported by donations from church members, as well as grants that are written through MCARES and the Public Health District HIV/AIDS program. In addition, MCARES gives $100 a month, and Mr. Jones' salary is paid by the Public Health District.

To appreciate this local MCC's AIDS Ministry, it is important to understand the context in which this ministry exists. Waco is an "overgrown country town of 100,000, just 100 miles south of Dallas, and 100 miles north of Austin," according to Jones. Waco is the home of the largest Southern Baptist college in the world, Baylor University, as well as Texas State Technical College, and McLennan Community College. Industry includes M&M Mars, Chrysler Technologies, and Aerospace Technologies. Jones states, "Waco is very influenced by Baylor and the Southern Baptists. There are three church here with over 5,000 very close-minded members each. The gay community is very closeted, although at the two bars, there is a fairly large community who are out to each other, but only at the bars."

Ms. Dunlap states, "Waco is a conservative community, so we have a large number of men who have sex with men, and are married to women. In our street outreach program, one of our targets is parks where men go to pick up other men. There we come across some Hispanics, but more African-Americans, and even more whites."

The Public Health District has identified 158 persons living with HIV in Waco. Sixty-one of these persons are active clients of the HIV/AIDS Health Services. According to Ms. Dunlap, "We mimic the nation in the percentage of minorities infected with HIV. Approxi-

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Waco, Texas

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mately 14% of our clients are women, 11% are Hispanic, 28% are African-American, and 61% are white." Jones asserts that the reporting by doctors is not very good, and estimates of the real number of HIV-positive persons in Waco run towards 1200. There are only two physicians in Waco who will treat persons with HIV/AIDS, and these two will take Medicaid. So a large number of patients are seen at the Family Practice Clinic.

MCC Waco's AIDS Ministry exists in a church where there has not been a large number of members or friends living with HIV/AIDS, and yet the pastors and church members have still created an AIDS ministry which rivals that of many larger MCC's. Only recently has the church membership been directly affected. In March, 1992, a devoted member died of complications from AIDS only nine days after finding out he had HIV. Then on October 31, 1992, the vice-moderator of the church succumbed to the complications of AIDS. Now Alan Jones is the only HIV+ member of the church, that they are aware of. "Waco is still in the mode of 'nobody needs to know,'" Alan says. "It's hard to be open here. But people in the church have been wonderful, helping to build shelves for the food bank, decorate the activities center, or even taking the volunteer training classes with the County. We put on Thanksgiving and Christmas dinners for our clients, and over 25 people showed uo!"

Ms. Dunlap, a married heterosexual woman, absolutely glows when she talks of MCC Waco: "That church, however small, has made a huge difference and impact on HIV services, and on me personally. They've made their voices heard in the process. The church provided support for us in the early years, not only financially (as best they could), but they were here saying, 'We agree with what you're doing.' Or if something wasn't going right, they would let us know that in their own way too. The times when I've attended services there, I was always greeted with warmth and compassion. At memorial services, the grieving process was facilitated. I have nothing but positive things to say about that group."

In a setting where Southern Baptists dominate, and it might be expected that MCC could not accomplish a great deal in AIDS Ministry, MCC Waco has had an enormous influence on that city's services to people with HIV/AIDS, and has created an AIDS Ministry which is an effective and powerful witness to what God can do when people open their hearts and lives to serve people who might otherwise be forgotten or ignored. ▼

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Treatment Issues: The council will see enactment of two pieces of legislation: 1) to empower the National Institutes of Health Office of AIDS Research with administrative and budget authority to be truly effective in managing the research program and 2) to mandate a comprehensive 5-year research plan.

Appropriations: The council will seek to fulfill President Clinton's pledge to achieve:

*full funding for the Ryan White CARE Act
*full support for NIH's AIDS budget request
*more prevention dollars for community-based organizations to implement a revamped prevention program
*fullfunding of the AIDS Housing Opportunities Act at $156 million. ▼

Medical Notes

Patients' Own Immune Cells Used In HIV Experiment

The U.S. National Institute of Allergy and Infectious Diseases (NIAID) has begun to evaluate the treatment of HIV-infected persons with large numbers of their own HIV-fighting immune cells grown in the laboratory. The study will assess the safety and feasibility of infusing HIV-infected persons with cytotoxic "killer" T cells that have been taken from their blood selected for their ability to kill HIV-infected cells and cultured in the laboratory.

"Cytotoxic T cells, sometimes called killer T cells, are important weapons in the body's immune defense against viruses, including HIV, that have infected cells," explains Anthony S. Fauci, M.D., NIAID Director. "Previous studies suggest that patients who progress to the late stages of HIV infection may lack functional cytotoxic T cells."

Between 15 and 24 patients will take part in the study at the New England Medical Center in Boston, Mass.

Study Examines Role of AZT Therapy for Early, Primary HIV Infection

Scientists will determine whether AZT will benefit people newly infected with HIV in a trial sponsored by NIAID. The new trial will address if daily AZT treatment delays the progression to AIDS from early HIV infection. This primary stage, characterized by flu-like symptoms, typically occurs two to twelve weeks after exposure to the virus.

"In the first weeks of an HIV infection, few clues exist for physicians to determine if someone is infected," says Manette T. Niu, M.D., medical officer of the study in NIAID's Division of AIDS. "People don't form antibodies to HIV until two to six months after infection - some weeks after the early, primary infection period."

Because of this lack of early, detectable antibodies, conventional HIV blood tests will not reveal primary infection. Instead, Dr. Niu and her colleagues will screen would-be participants with a special blood test that looks for a protein part of HIV called p24. This protein is present in the blood in measurable levels during the first six weeks of HIV infection. People who already have antibodies to HIV are not eligible to enroll in the trial.

During the study, investigators will randomly assign participants to receive either 1,200 milligrams of AZT or a placebo each day for 24 weeks and then be followed until the development of AIDS. The researchers will determine whether AZT slows the decrease of the CD4+ T cells, which HIV targets and kills.

Eight patients will be enrolled at sites throughout the US. Men and women age 13 or older can participate, but pregnant women cannot. The first four sites are: Brown University, Providence, RI, Cedars-Sinai Medical Center, Los Angeles, CA, Department of Veterans Affairs Medical Center, Palo Alto, CA, and Massachusetts General Hospital, Boston.

For more information on this study, call 1-800-TRIALS-A (1-800-874-2572) from 9 a.m. to 7 p.m., EST. All calls are confidential. ▼